

Grand Forks Session – Written Feedback

1. In what ways do you find information about programs and services available to you and your child?
 - From our special ed dept. and North East Human Services
 - From our social worker/case mgr. at NorthEast Human Services
 - Research on the internet
 - Developmental DD case management, only the good ones pass on the info to parents
 - Through other parents
 - Friends, co-workers
 - Internet, calling NE Human Services, calling other service providers, talking to other parents, contacting “knowledgeable people” and chaining names until you run out or get an answer
 - Through infant development and public health
2. Who is the service provider who primarily coordinates care for your child? (by title or profession)
 - Marilyn Arneson from Northeast or Wert (Case Manager) for our children
 - Dr. Eric Lunn, Dr. Sobus (from Altru)
 - Myself – I type the letter to the pediatrician with doctors dates, times of appointments and he forwards it to the state for approval
 - audiologists – Altru, GF school system, SLP-Central Valley School
 - No one – various organizations can provide limited coordination – I provide all the actual coordination
 - Me, the mother, my public health nurse, infant development
3. What other health care professionals or service providers assist in organizing or coordinating care for your child?
 - Just our normal physicians and physical therapist for Lorie
 - Independent living centers, like the one I work at gives parents info and walk them through the process
 - Primarily ND and myself
 - I use DD case management. Other organizations are consulted if needed. Currently ED, DD and welfare and the school are committed to planning for my daughter’s return home
 - Public health, infant development, support systems, Meritcare Home nursing

4. What do you like about the way your child's care is coordinated?
- Well actually, we don't presently have a lot of health care concerns
 - Very good. Dr. Sobus and Dr. Lunn coordinate our son's care very well
 - I like myself doing this. I can present how important and being in charge and know if it is being done.
 - Nothing – mostly directed and guided by myself
 - it can be done by a parent still if persistent. I worry that the option with become unavailable.
 - Overall, it's good. But I do run into snags
5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?
- 4, 4/5 (the health care with Altru is very good. They will refer if they feel my son's needs cannot be met at Altru. Need pediatric neurology), about 1-2 in ND – in Minneapolis about 5, 5, 2-3, 3.5 (I get a lot of health care, but there are some needs that are not met)
6. What methods are in place to help assure quality care for your child?
- I'm not sure other than my wife and I
 - Parents and health care professionals
 - I try to doctor as much in the area for tests and evaluations and then take that info with me. I feel the state wastes more in testing and medications than going to a specialty facility that knows what to do and is aware of non-necessary testing
 - Myself
 - Laws, personal integrity
 - Medicaid – insurance wise, infant development until 3 years
7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?
- Yes – St. Paul for surgery
 - Yes – Minneapolis for specialized mental health services – none useful in ND after several trials. Moorhead for psychiatric services – available and specialized
 - No
 - Yes - usually Minneapolis to the specialty hospitals and clinics
 - Yes, we initially went to the sister Kenny Institute to have a ? pump. Now Altru does this procedure.
 - Yes – Jamie went to Abbot North East in the Twin Cities for a Rizotonic about 10 years ago.

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

- None
- Voluntary placement of my child in Residential Treatment Center – good service, ACT team – bad outcome, not useful
- Money for hearing aides and appointments
- Medicaid has been really limited on approvals for out of state care
- DD case management
- Family subsidy
- For just about all their needs and services related to their needs. Angie has Down Syndrome and Jamie has cerebral palsy.

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

- Medicaid, northeast, NDAD
- yes – none except the voluntary placement
- CSHS
- Family subsidy, Medicaid
- Medical assistance, family subsidy, NDAD

10. Have you ever been denied health care services because of financial barriers?

- No
- The only barrier is that I can't afford all of it – too high income, and services are \$9,000/month
- No – except with hearing aides unless we paid for them – had to borrow that money from grandparents
- No
- No
- No

11. What one recommendation do you have for improving the care provided for your child and family?

- More financial support
- Information and referral that is accurate, timely and accessible
- Educating providers and their nurses regarding financial and emotional support for parents
- We don't need care coordination but more emotional, financial help
- Medical assistance needs to look at things that parents feel are medically essential. We have been denied a toilet seat because they said it is a personal hygiene device. To our son, this device is medically essential for him to function properly
- Pull-ups. Medical assistance only pays for the cheapest pull-ups – these do not meet our son's needs. He had to come home wet at times from school. We now purchase the better ones for him
- More respite care opportunities